United Nations A/HRC/31/63

General Assembly

Distr.: General
18 January 2016

Original: English

Human Rights Council
Thirty-first session
Agenda item 3
Promotion and protection of all human rights, civil, political, economic, social and cultural rights, including the right to development

Report of the Independent Expert on the enjoyment of human rights by persons with albinism

Note by the Secretariat

The Secretariat has the honour to transmit to the Human Rights Council the first report of the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, prepared pursuant to Council resolution 28/6. In the report, the Independent Expert presents a number of reflections on the situation of the enjoyment of human rights by persons with albinism as well as on her vision for her work as Independent Expert, including how she intends to fulfill the requirements of her mandate and the issues she wishes to address as a matter of priority.

GE.16-00616(E)

Please recycle

Report of the Independent Expert on the enjoyment of human rights by persons with albinism

Contents

		Page
I.	Introduction	3
II.	Setting up the mandate	3
	A. Mandate of the Independent Expert	3
	B. Overarching considerations of the mandate	4
	C. Methods of work	4
III.	Background information on albinism	5
IV.	Areas of concern and priority issues	6
	A. Witchcraft and related offences	6
	B. Discrimination	9
	C. Disability	10
	D. Health	10
	E. Women and children	11
V.	Independent Expert's vision for the mandate	12
	A. Develop and strengthen specific measures to end and prevent attacks	12
	B. Define applicable international legal frameworks	13
	C. Strengthen concerted implementation efforts	13
	D. Increase awareness and understanding of the condition of persons with albinism	15
VI.	Conclusions	15

I. Introduction

1. The present report is submitted by the Independent Expert on the enjoyment of human rights by persons with albinism, Ikponwosa Ero, pursuant to Human Rights Council resolution 28/6.

2. On 3 July 2015, the Human Rights Council appointed Ms. Ero of Nigeria as the first mandate holder on the enjoyment of human rights by persons with albinism. She assumed her duties on 1 August 2015. The Independent Expert would like to thank the Council for the trust that it has placed in her with the important task of fulfilling this mandate as the first mandate holder. She commits herself to do so in an impartial and constructive manner and in accordance with the requirements set forth by the Council. She would also like to express her gratitude to the numerous civil society organizations with which she has already engaged and to affirm her strong commitment to her role as Independent Expert.

3. This is the Independent Expert's first report to the Human Rights Council. In it, she reflects on the degree to which persons with albinism are able to enjoy their human rights, presents her vision for the mandate and identifies matters of priority.

II. Setting up the mandate

A. Mandate of the Independent Expert

4. The mandate of the Independent Expert on the enjoyment of human rights by persons with albinism was established by the Human Rights Council on 26 March 2015 in resolution 28/6, as follows: to engage in dialogue and consult with States and other relevant stakeholders; to identify, exchange and promote good practices relating to the realization of the rights of persons with albinism and their participation as equal members of society; to promote and report on developments, challenges and obstacles relating to the realization of the enjoyment of human rights by persons with albinism and to make recommendations in that regard to Council; to gather, request, receive and exchange information and communications from and with States and other relevant sources; to conduct, facilitate and support the provision of advisory services, technical assistance, capacity-building and international cooperation in support of national efforts; to raise awareness on the rights of persons with albinism and to combat stereotypes, prejudices and harmful traditional practices and beliefs; to promote awareness of the positive contributions of persons with albinism and to inform them about their rights; and to report to the Human Rights Council, starting at its thirty-first session, and to the General Assembly.

5. In discharging the mandate, the Independent Expert will be guided by Council resolution 23/13 on attacks and discrimination against persons with albinism and resolution 24/33 on technical cooperation for the prevention of attacks against persons with albinism. The Independent Expert will also base her work on the preliminary report of the Office of the United Nations High Commissioner for Human Rights (OHCHR) on persons with albinism (A/HRC/24/57), submitted to the Council at its twenty-fourth session, and the report of the Human Rights Council Advisory Committee on the study on the situation of human rights of persons living with albinism (A/HRC/28/75), submitted to the Council at its twenty-eighth session. At the regional level, the African Commission on Human and Peoples' Rights resolution 263 on the prevention of attacks and discrimination against persons with albinism will also be at the core of the work of the Independent Expert. In its resolution 69/170, the General Assembly proclaimed 13 June as International Albinism Awareness Day.

B. Overarching considerations of the mandate

6. The Independent Expert will be guided by the following considerations in all aspects of her work:

(a) Participation: the Independent Expert intends to carry out her work in a participatory, consultative and open manner, actively involving persons with albinism and organizations working on albinism;

(b) Constructive dialogue: the Independent Expert will implement her mandate in a spirit of cooperation, through earnest and constructive dialogue, focusing on requests for technical assistance and on the promotion of best practices;

(c) Inclusiveness: the Independent Expert will address the obstacles, such as attacks and discrimination, to the enjoyment of all human rights by persons with albinism, including the right to the highest attainable standard of physical and mental health and the right to education, as well as the barriers to the enjoyment of their human rights linked to disability;

(d) Global perspective: the Independent Expert will work in an inclusive manner to address globally barriers to the enjoyment of human rights by persons with albinism, while recognizing that the obstacles to the realization of such rights may differ from region to region;

(e) Gender perspective: women with albinism and mothers of persons with albinism have been particularly affected by discrimination. In accordance with her mandate, the Independent Expert will pay specific attention to the challenges and needs of women and girls in addressing the multiple, intersecting and aggravated forms of discrimination faced by them.

C. Methods of work

7. In accordance with her mandate, the Independent Expert intends to carry out her work within the areas usually targeted by special procedure mandate holders, including the promotion of good practices, country assessments, communications regarding alleged human rights violations, awareness-raising activities and thematic studies. In doing so, she will endeavour to work closely with other mandate holders, including through joint communications, close cooperation with regard to research on the situation of persons with albinism, as well as coordination of consultative meetings and events. She will also endeavour to provide technical assistance and concrete recommendations to facilitate legal reforms and policymaking through the compilation and promotion of best practices for both short- and long-term responses to the human rights issues faced by persons with albinism. To do so, the Independent Expert will, funding permitting, conduct in-depth stakeholder consultations.

8. In the implementation of her mandate, the Independent Expert will seek to work in close cooperation with other mandate holders, in particular the Special Rapporteur on the rights of persons with disabilities, with the office of the Special Representative of the Secretary-General on Violence against Children, with regional mechanisms, such as the African Commission on Human and People's Rights, with civil society, including organizations of persons with albinism throughout the world, and with all relevant United Nations agencies.

9. Facilitating cooperation and building bridges at the local, regional and national levels will also be a focus of the Independent Expert, as projects and initiatives too often take place in isolation. Best practices and experiences in tackling discrimination against

persons with albinism or facilitating access to health, for example, would benefit from a coordinated exchange at both national and international levels. In addition, certain States in a region share similar challenges and obstacles with regard to attacks against persons with albinism, for example, and although efforts have been made and steps taken in the countries most affected, there has been little international cooperation and discussion to share experiences, both positive and negative, in addressing attacks against persons with albinism. The Independent Expert will therefore endeavour to provide platforms to coordinate efforts in order to efficiently and sustainably address challenges in that area.

10. A crucial element of the Independent Expert's mandate in the coming year will be assessing the current situation of persons with albinism and identifying best practices through country visits. During her mandate, the Independent Expert would like to undertake country visits in areas most affected by human rights violations of persons with albinism, namely sub-Saharan Africa. She hopes that all Governments will welcome such visits and envisages that the outcome of country visits, including the best practices gathered, would not only feed into thematic studies, but also practically inform her compilation of best practices.

11. The Independent Expert will focus on enhancing the visibility of the mandate and on strengthening its cooperation with civil society organizations.

III. Background information on albinism

12. Albinism is a rare, non-contagious, genetically inherited condition that affects people worldwide regardless of ethnicity or gender. It results from a significant deficit in the production of melanin and is characterized by the partial or complete absence of pigment in the skin, hair and eyes. In order for a person to be affected by albinism, both parents must carry the gene and, in that case, there is a 25 per cent chance that a child will be born with albinism at each pregnancy. The proportion of persons affected by albinism in the world differs from region to region. For example, in North America and Europe, it is estimated that 1 in 17,000 to 20,000 people are affected by the condition,[1] while in sub-Saharan Africa, 1 in 5,000 to 15,000 could be affected, with specific countries having a much higher tendency, including estimated rates of 1 in 1,400,[2] and about 1 in 20 persons in the general population carrying the gene for albinism. Other studies suggest that in specific groups in Panama or in the Pacific region, the rate of people affected could be as high as 1 in 70 to 1 in 125.

13. There are different types of albinism. The most common and visible type is oculocutaneous albinism (OCA), which affects the skin, the hair and the eyes. Within this type, there are subtypes, which reflect varying degrees of melanin pigment deficiency in an individual. The main subtypes of OCA are tyrosinase negative albinism (OCA1) and tyrosinase positive albinism (OCA2). In OCA1, there is little or no production of melanin and it is often characterized by white hair and opaque or transparent irises. In the more prevalent, particularly in African countries, OCA2, some melanin is produced and it is characterized by yellow-blonde or sandy-coloured hair and grey to light brown irises. A less common form of albinism is ocular albinism which affects the eyes alone, while albinism

[1] National Organization for Albinism and Hypopigmentation, "What is Albinism?" Information bulletin, available at www.albinism.org/site/c.flKYIdOUIhJ4H/b.9253761/k.24EE/Information_Bulletin__What_is_Albinism.htm; see also A/HRC/24/57, para. 14.

[2] In 2005, World Health Organization (WHO) carried out a pilot survey on albinism in African countries, results were published in 2006; see also A/HRC/24/57, para. 14.

accompanied by Hermansky-Pudlak syndrome is another less common form, which is characterized by bleeding disorders, bowel (colitis) and lung diseases.

IV. Areas of concern and priority issues

14. Persons with albinism face discrimination and barriers that restrict their participation in society on an equal basis with others every day. Due to those many challenges, persons with albinism throughout the world are unable to enjoy the full range of human rights and the same standards of equality, rights and dignity as others. While some of those challenges are global, others have predominantly been identified in certain regions. There are legal and policy foundations to most of the human rights violations faced by persons with albinism, however, they have not yet been consolidated and there are no specific instruments or guidelines on the enjoyment of human rights by persons with albinism — a gap that the Independent Expert wishes to address in consultation with stakeholders.

15. As an initial step, the mandate holder will outline, in broad strokes, some of the obstacles with which persons with albinism are confronted. The obstacles identified constitute the main areas of concern and priorities of the mandate holder and include human rights violations such as attacks, desecration of graves, trafficking of body parts, displacement, discrimination against persons with albinism, as well as human rights violations based on disabilities, challenges in the right to the highest attainable standard of health and the right to education. The Independent Expert would also like to draw attention to the particularly concerning situation of women and children with albinism.

A. Witchcraft and related offences

16. It has been widely reported and documented that persons with albinism are hunted and physically attacked due to prevailing myths such as the misbelief that their body parts, when used in witchcraft rituals and potions or amulets, will induce wealth, good luck and political success. Other dangerous myths that facilitate the perpetration of attacks are those linked to perceptions of their appearance, including misbeliefs and myths that persons with albinism are not human beings, but ghosts, that they are subhuman and that they do not die, but disappear. An increase of those attacks, referred to as "ritual attacks", has been reported by civil society during periods of political elections.

17. Attacks against persons with albinism and corollary issues of displacement and trafficking in body parts violate the right to life, the right to security of person and the prohibition of torture and ill-treatment, as enshrined in various international human rights treaties. As reported by OHCHR, whether any particular ritual killing or attack against persons with albinism is attributable to a State agent needs to be determined on a case-by-case basis. Nevertheless, the State violates its obligation to ensure the right to life and the prohibition of torture and ill-treatment by failing to take appropriate measures to prevent, investigate, prosecute, punish or redress.[3]

18. In response to the issue, several treaty bodies have called for immediate action to end the attacks. These include the Human Rights Committee,[4] which recommended that affected States strengthen efforts to halt attacks on the physical integrity of persons with albinism, ensure the conduct of timely investigations and strengthen awareness-raising

[3] See A/HRC/24/57, para. 31.

[4] See, for example, CCPR/C/TZA/CO/4, para. 15; CCPR/C/BDI/CO/2, para. 9; and CCPR/C/KEN/CO/3, para. 17.

campaigns. Similarly, the Committee on the Rights of the Child,[5] the Committee on the Elimination of Discrimination against Women,[6] the Committee on the Right of Persons with Disabilities[7] and the Committee on Economic, Social and Cultural Rights,[8] in reiterating the right to life and non-discrimination, have called for immediate action to end such attacks. In their resolutions, the Human Rights Council and the African Commission on Human and Peoples' Rights have also called for immediate action to stop attacks and discrimination against persons with albinism.[9]

19. The Independent Expert intends to address the impact of witchcraft on the human rights of persons with albinism as a harmful traditional practice and as one of the root causes of ritual attacks. This will require careful understanding, definition and delineation of the practice, the form it takes and the effects it has on persons with albinism.

I. Attacks

20. The appearance that ensues in albinism, in particular the lack of melanin in the skin, eyes and hair, exposes tens of thousands of persons to stigma and discrimination across the world. It is reported that, in Africa, attacks directed at persons with albinism are usually carried out with machetes, resulting in severe mutilation or death. In most cases, the persons attacked are dismembered; body parts such as fingers, arms, legs, eyes, genitals, skin, bones, the head and hair have been severed from the body and taken. In several of those cases, body parts have been hacked off while the person was alive. Reportedly, there is a corollary witchcraft belief that it is preferable to harvest body parts from live victims because screams increase the potency of the potion for which the parts are used.[10] Possible human sacrifices of persons with albinism have also been reported, including through immolation.

21. Since 2007, civil society organizations have reported hundreds of attacks against persons with albinism in 25 countries. All of those physical attacks appear to be, at least in part, related to the erroneous beliefs and myths linked to witchcraft practices.

22. The large number of cases reported by civil society no doubt represents a fraction of the attacks against persons with albinism. The secrecy that often surrounds ritual attacks, the complicity of family members in certain cases, the difficulty in accessing data owing to the fact that most attacks occur in rural environments, as well as the low response to such attacks may serve as hindrances to the reporting and visibility of attacks. Moreover, discrimination against persons with albinism and significant impunity may also have an impact on the reporting of such cases. Impunity was also highlighted by OHCHR, which had received information that persons with albinism faced significant difficulties in having their cases brought to justice.[11] In a similar vein, the Special Representative of the Secretary-General on Violence against Children has stated that the human rights violations committed against children with albinism are of the highest severity. Discrimination, harassment and violence, including cases of mutilation and murder, are often met with passivity and rarely reported, as they often take place in remote areas and because such children are perceived as

---

[5] See, for example, CRC/C/BDI/CO/2, paras. 30 and 34; CRC/C/TZA/CO/3-5, paras. 25-26 and 29-31; CRC/C/OPSC/TZA/CO/1, para. 20; and CRC/C/GNB/CO/2-4, paras. 28-29.

[6] See, for example,CEDAW/C/COD/CO/6-7, paras. 35 (c) and 36 (b); CEDAW/C/TZA/CO/6, paras. 45-46; CEDAW/C/SWZ/CO/1-2, paras. 22-23; and CEDAW/C/MWI/Q/7, paras. 20-21 and 44-45.

[7] See, for example, CRPD/C/KEN/CO/1, paras. 19-20.

[8] See, for example, E/C.12/COD/CO/4, paras. 19 and 28; and E/C.12/TZA/CO/1-3, para. 5.

[9] See Human Rights Council resolutions 23/13 and 24/33; and African Commission on Human and Peoples' Rights resolution 263.

[10] Simon Fellows, *Trafficking Body Parts in Mozambique and South Africa* (Mozambique, Human Rights League, 2010).

[11] See A/HRC/24/57, para. 53.

bringing bad luck and being a source of shame to even their own families and communities. Mutilation and murders of children with albinism are mostly met by social silence and indifference.[12]

23. Challenges to ending impunity may include lack of confidence in the law enforcement or judicial system owing to fear of reprisals or stigmatization, ignorance of their rights or lack of financial resources. Barriers also subsist at the investigations level, where there might be difficulties in finding witnesses owing, inter alia, to stigmatization and discrimination, fear of reprisals (including through witchcraft), lack of comprehensive witness protection programmes, involvement of family members and lack of financial resources. Barriers subsisting at the prosecution stage may include restrictions in the implementation of the right to a fair trial and due process, such as the lack of adequate legal representation. In addition, even when perpetrators are successfully prosecuted, it has been reported that too often the sentence pronounced is not proportionate to the gravity of the crime committed. Such outcomes can undermine the trust of victims in the justice system and lead to a reduction in the number of cases reported. Other barriers to ending impunity can be found at the policy and legislative levels, including the need for a clear and adequate legal framework regarding albinism that covers attacks and the impact of witchcraft on the human rights of persons with albinism.

2. Trafficking in body parts

24. It has been reported that there is a market for body parts of persons with albinism. The body parts are reportedly sold both locally and across borders. The prices of body parts reportedly range from $2,000 for a limb to $75,000 for a "complete set" or a corpse.[13] Civil society reports indicate that, motivated by those prices, family members and communities have sold, or attempted to sell, persons with albinism, thereby fuelling the supply side of this macabre trade. The prices also indicate the involvement of wealthy individuals as they stand in sharp contrast to the average annual income per capita reported in the affected regions. Given the underground nature of this trade, further study is needed to assess its scope and extent and, on that basis, to identify effective measures.

25. Recent cases of body-parts trafficking that were brought to the attention of the Independent Expert by civil society include cases where law enforcement agencies acted promptly and were able to prevent the sale and save the persons with albinism involved. In a few other cases, however, the body parts were harvested and have still not been recovered.

3. Related human rights violations

26. Attacks against persons with albinism in some areas have caused hundreds of persons, particularly women and children, to flee their homes and seek refuge in temporary shelters. This has been the case in remote border areas or in areas particularly affected by attacks.

27. In addition, as a protection measure, children have been transported to shelters, including police stations, schools or centres built for other needs, such as for people living with leprosy. Most of these shelters were neither designed nor prepared for an influx of persons with albinism, nor are they equipped to address the special needs of persons with albinism. Reports show that inhabitants with albinism are exposed to early skin cancer risk and various forms of abuse. Furthermore, as pointed out by the Human Rights Council

[12] Ibid., para. 54.

[13] See International Federation of the Red Cross and Red Crescent Societies, *Through albino eyes: The plight of albino people in Africa's Great Lakes region and a Red Cross response*, Advocacy report (2009), available at www.ifrc.org/Global/Publications/general/177800-Albinos-Report-EN.pdf.

Advisory Committee in its study on the situation of human rights of persons living with albinism, an assessment by the OHCHR field presence of the situation of displaced persons with albinism in Burundi showed the precarious security situation of some of them and the negative impact of the measure on the right to an adequate standard of living.[14]

28. According to information received, the erroneous beliefs and myths, including certain witchcraft practices, have led to the desecration of graves of persons with albinism. Such desecrations have been reported in at least seven countries in Africa. In the cases reported, graves of persons with albinism were open and body parts or bones were stolen.

B. Discrimination

29. One of the main barriers to the implementation of the human rights of persons with albinism is discrimination and stigmatization, both of which are historically and culturally entrenched. Information on discrimination against persons with albinism has been received from around the world. However, the expression and severity of the discrimination faced by persons with albinism vary from region to region.

30. In so-called Western countries, persons with albinism face the effects of entrenched misconceptions and misunderstandings of the condition. Discrimination through mockery or bullying of school-age children owing to their appearance has been reported. Given the relative rarity of albinism, popular culture, such as movies (a majority of which depict albinism negatively), are often the sole source of information on the condition for the majority of the population, fuelling widespread misconceptions and misunderstanding of the condition.

31. Bullying of school-age children owing to their appearance has also been reported in other regions of the world, such as in sub-Saharan Africa. However, in that region, discrimination takes more extreme forms, including infanticide, physical threats and attacks. Lack of information on the condition facilitates the spread of myths to explain albinism, most of which are erroneous and in some cases dangerous, including myths that people with albinism are ghosts or the result of conception during menstruation or the result of a general curse. Life in that context could be described as a cycle of discrimination. Civil society has reported that ostracism of entire families owing to the strong negative connotation of the birth of a child with albinism, perceived as a source of misfortune in certain regions, contributes to infanticide and abandonment of children. Where there are no systematic birth and death records, identification and reporting of such cases are even more difficult. In some regions, children with albinism drop out of school for reasons linked to stigma and because no reasonable accommodation is made for the vision impairment often resulting from albinism. A lack of education combined with widespread absence of health information often lead persons with albinism to employment outdoors with no protection from the sun, which exposes them to a high risk of skin cancer.

32. In the Pacific Islands, it has been reported that people with albinism suffer comparable human rights-related issues with regard to lack of access to information and support for health conditions, vision problems and cultural isolation. There is little verified information on the human rights situation of persons with albinism in Asia, South America and the Caribbean. The Human Rights Council Advisory Committee stressed that the absence of information on albinism in other regions should not be interpreted to mean that there is no problem of discrimination, stigmatization and violence in those regions. Lack of

[14] See A/HRC/28/75, para. 24.

sufficient knowledge remains a significant barrier to tackling discrimination, stigmatization and violence.[15]

33. Discrimination, stigma and bullying of persons with albinism owing to their appearance have been reported in all regions of the world, to varying degrees. Such discrimination has been described as discrimination based on skin tone or shade, including within the same ethnic group. While discrimination based on skin colour is an everyday reality for most persons with albinism, discourse on discrimination based on colour has rarely been applied to albinism. This is for various reasons such as the lack of visibility of albinism, until very recently, the lack of understanding of what persons with albinism experience and lastly, but perhaps most significantly, strong historical ties of racial discrimination discourse to race or ethnicity. Yet, there is potential to address albinism under the International Convention on the Elimination of All Forms of Racial Discrimination, as the governing concept is not "race" but "racial discrimination", which may be based on any of five "grounds": race, colour, descent, national origin and ethnic origin.[16]

C. Disability

34. The term "persons with disabilities" under the Convention on the Rights of Persons with Disabilities has a broad scope and includes any person with a long-term physical, mental, intellectual or sensory impairment, which, in interaction with various barriers, may hinder his or her full and effective participation in society on an equal basis with others.

35. Lack of melanin in the eyes results in high sensitivity to bright light and significant vision impairment, with the level of severity varying from one person to another. This vision impairment often cannot be completely corrected. In some countries, this has led to the categorization of persons with albinism as legally blind, which enables them to access the national legal frameworks in the field of the rights of persons with disabilities, including measures related to access to health and education.

36. Legal frameworks for the enjoyment of human rights by persons with disabilities, including the Convention, could address issues faced by persons with albinism on the basis of their vision impairment. The Convention in particular identifies areas where adaptations have to be made so that persons with disabilities can fully enjoy their human rights, including access to education, employment, information and health care. Furthermore, the Convention has established as principles respect for inherent dignity, equality of opportunity, full and effective participation and inclusion in society and non-discrimination. On that basis, urgent measures could be implemented to address pressing issues relating to the visual impairment of persons with albinism. However, those measures would need to be combined with other measures designed to address other forms of discrimination faced by persons with albinism as well as to address attacks and to ensure access to health care.

D. Health

37. One of the most serious health implications of albinism is the vulnerability to skin cancer. Skin cancer remains a life-threatening condition for most persons with albinism. Statistics on the issue are mostly from Africa and they indicate a worrying trend. Some

[15] See A/HRC/28/75, para. 43.

[16] See OHCHR and International Organization of la Francophonie, "Expert meeting on persons with albinism: violence, discrimination and way forward", outcome report, 24 September 2014, para. 33.

reports indicate that most persons with albinism die from skin cancer between the ages of 30 and 40 years.[17] A recent sampling of 77 persons with albinism from different African countries seems to support the reported trends. Of the 77, 43 had 239 pre-cancerous lesions and 3 required immediate surgical attention.[18] This sample indicates the scale of the problem in the region and the need for immediate attention.

38. Studies often link the prevalence of skin cancer to factors such as the lack of basic understanding of albinism, particularly by persons with albinism and their families. For example, it is not uncommon for parents to put a newborn with albinism out in the sun for hours. Displaced persons with albinism are exposed to a heightened risk of skin cancer as they are mostly outside of their usual environment and have limited means to address their health needs. Also at particular risk of developing skin cancer are persons with albinism who work outdoors, such as farmers or traders. Such outdoor occupations also emphasize the link between the risk of contracting skin cancer and poverty.

39. The general lack awareness of the link between albinism and skin cancer means that the prevalence of the condition has led to the belief that pre-cancerous and cancerous lesions on a person with albinism is a necessary part of albinism. The appearance of such lesions on persons with albinism adds more stigma to an already stigmatized appearance and exposes person with albinism to further discrimination, particularly when seeking employment.

40. Yet, there are several effective ways to prevent skin cancer, including the use of sun protection cream, which is topically applied, or wearing sun-protective clothing with long sleeves, wide-brimmed hats and sunglasses. Given the accessibility and effectiveness of protective clothing, skin cancer could be significantly prevented at little cost with the right level of public education and early intervention programmes targeting persons with albinism and their families.

E. Women and children

41. Women and children with albinism are particularly vulnerable as they are exposed to intersecting and multiple forms of discrimination. In addition, children are particularly targeted for ritual killings and women are sometimes victims of sexual violence.[19] The Human Rights Council Advisory Committee also stressed the specific challenges faced by women and children with albinism in that regard.[20]

42. Children with albinism are often particular targets of attacks due to the witchcraft-based belief that the innocence of a victim from whom body parts are taken increases the potency of the potion for which the body parts are used. Cases reported by civil society indicate that children constitute a large proportion of victims of ritual attacks.

43. As noted by the Special Representative of the Secretary-General on Violence against Children, children with albinism are at high risk of abandonment, stigmatization and

---

[17] See, for example, Andres E. Cruz-Inigo, Barry Ladizinsky and Aisha Seth, "Albinism in Africa: stigma, slaughter and awareness campaigns", *Dermatologic Clinics*, vol. 29, No. 1 (January 2011), pp. 79-87 (citing J. Luande, Claudia I. Henschke and Nassoro Mohammed, "The Tanzanian human albino skin. Natural history", *Cancer*, vol. 55, Issue 8 (15 April 1985) pp. 1823-1828).

[18] Indicative sampling of 77 leaders and activists with albinism, Clinic Data Report, unpublished, "Standing Voice", Pan African Albinism Conference, held in Dar-es-Salaam, United Republic of Tanzania,19-22 November 2015.

[19] See A/HRC/24/57, para. 74.

[20] See A/HRC/28/75, paras. 35-38.

marginalization as a result of their appearance, and due to disability factors associated with their condition, such as impaired eyesight and sensitive skin.[21]

44. Discrimination against women takes various forms. Women with albinism are reportedly victims of targeted acts of sexual violence spurred by the myth and misbelief that sexual intercourse with a woman with albinism can cure HIV/AIDS. Furthermore, women who give birth to a child with albinism may face ostracism and discrimination. They are also exposed to rejection by their husbands or partners, accused of adultery or infidelity and blamed for giving birth to a child who is generally seen as a curse or a bad omen. The rejection of mothers of children with albinism exposes them to poverty and isolation and increases the vulnerability to attacks of both mother and child with albinism.

V. Independent Expert's vision for the mandate

A. Develop and strengthen specific measures to end and prevent attacks

45. The Independent Expert intends to identify and consolidate the measures to end and prevent attacks to persons with albinism in consultation with States, civil society, international and regional bodies and agencies as well as other stakeholders. The specific measures identified will be based on those already identified, particularly those adopted by the African Commission on Human and Peoples' Rights, namely:[22]

(a) Effective protection of persons with albinism and members of their families;

(b) Conduct of impartial, speedy and effective investigations into attacks against persons with albinism;

(c) Prosecution of perpetrators of attacks against persons with albinism;

(d) Ensuring that victims and members of their families have access to appropriate remedies;

(e) Increased education and public awareness-raising activities;

(f) Inclusion of information in reports submitted by States parties to the African Commission on Human and Peoples' Rights under article 62 of the African Charter on Human and Peoples' Rights, on the situation of persons with albinism, including good practices in protecting and promoting the rights of persons with albinism;

(g) Promotion, in collaboration with relevant regional and international organizations, bilateral, regional and international initiatives aimed at protecting persons with albinism.

46. The Independent Expert is of the view that specific measures to end attacks against persons with albinism should include immediate investigation of allegations and prosecution of alleged perpetrators, legal representation and adequate protection for victims and witnesses and sensitization of the judiciary and law enforcement officers on the issue. Furthermore, protection measures for persons with albinism should be adopted and implemented in their communities. Victims of attacks should be provided with the appropriate remedy and redress, not only legal, but also social, psychological and medical. The Independent Expert will also seek the adoption of measures to prevent the trafficking in body parts, as well as specific measures for improving conditions at temporary shelters for

[21] See A/69/264, para. 34.

[22] African Commission on Human and Peoples' Rights resolution 263.

displaced persons with albinism and the execution of safe strategies for reintegrating them into their homes and communities. In that regard, she encourages international and regional cooperation.

B. Define applicable international legal frameworks

47. The Independent Expert considers it important to identify the applicable human rights legal framework and the key international human rights instruments that could both comprehensively and effectively address the human rights-related issues faced by persons with albinism in a sustainable way.

48. The Independent Expert will pay particular attention to the practices and legal approaches of countries to ensure the full enjoyment of human rights by persons with albinism. She envisages wide consultation particularly among persons with albinism on their views on discrimination. She will follow with interest debates on the ways to approach such issues at the national, regional and international levels. The Independent Expert looks forward to working closely with experts at the national, regional and international levels on related issues such as racial discrimination, disabilities, trafficking, health, minority issues, violence against women and children, cultural rights, harmful traditional practices, extrajudicial and summary executions and torture, most of whom have already contributed to the debate surrounding the enjoyment of human rights by persons with albinism.[23]

49. Such current multisectoral debates highlight the fact that the human rights challenges associated with albinism are multilayered and could be addressed by various human rights mechanisms. They also show the need for in-depth reflection with stakeholders to inform policymaking and better inform the ongoing work of the Independent Expert in fulfilling the mandate.

C. Strengthen concerted implementation efforts

1. Regional and international agenda

50. The Independent Expert intends to build on the work already done to address the enjoyment of human rights by persons with albinism at the international level, including the work of the Human Rights Council and of the African Commission on Human and Peoples' Rights through the provision of technical advice.

51. The findings of the Human Rights Council Advisory Committee will also guide the Independent Expert in her work. In its report to the Human Rights Council, the Advisory Committee stressed the need for increased engagement of international and regional mechanisms with the issue of persons with albinism and lamented that efforts, however, continue to be fragmented and only partially address the complexity of the human rights challenges that persons with albinism face. A more sustainable response, to bridge protection gaps and to ensure accountability for human rights violations committed against persons with albinism, is required.[24]

52. The Independent Expert looks forward to working closely with all special procedure mandate holders so as to harmonize efforts in addressing the many obstacles to the full

[23] See, for example, OHCHR, "Not ghosts, but human beings ... persons with albinism", press release, 4 May 2013, available at www.ohchr.org/en/NewsEvents/Pages/DisplayNews.aspx?NewsID=13294&LangID=E.

[24] See A/HRC/28/75, para. 61.

enjoyment of human rights by persons with albinism. She sees close connections between her mandate and those of other special procedures, such as the rights of persons with disabilities; the right to education; the right of everyone to the enjoyment of the highest attainable standard of physical and mental health; the issue of discrimination against women in law and in practice; violence against women; contemporary forms of racism, racial discrimination, xenophobia and related intolerance; and cultural rights. The Independent Expert also intends to work in close cooperation with the mandate holders on extrajudicial, summary or arbitrary executions; torture and other cruel, inhuman or degrading treatment or punishment; the sale of children, child prostitution and child pornography; and trafficking in persons, especially women and children.

53. The Independent Expert attaches great importance to the work of the United Nations human rights treaty bodies, many of which have addressed the obstacles faced by persons with albinism, and wishes to extend her full support and availability to cooperate with them on this topic.

54. The Independent Expert will also liaise closely with United Nations agencies, funds and programmes, regarding their work on persons with albinism. She wishes to stress the important role played by regional organizations, such as the African Committee of Experts on the Rights and Welfare of the Child, and looks forward to working closely with them.

55. In addition, the Independent Expert believes that States affected by attacks against persons with albinism may share similar challenges and obstacles, and notes that some have adopted certain measures in an effort to address the issue. The Independent Expert intends to encourage regional forums in order to exchange experiences, both positive and negatives, foster regional dialogue and the sharing of best practices in this regard.

2. National agenda

56. The Independent Expert recognizes that a very important part of the mandate is to support States in the development of their national efforts to advance the implementation of the rights of persons with albinism.

57. Guided by her mandate to identify, exchange and promote good practices relating to the realization of the rights of persons with albinism and their participation as equal members of society, she will strive to identify effective measures to address discrimination against persons with albinism at all levels, including with regard to access to health and education. This collection of best practices would address the protection and promotion of human rights of people with albinism and focus on issues beyond attacks, namely discrimination and equality.

58. In order to identify best practices, the Independent Expert intends to hold broad consultations with all stakeholders, including persons with albinism, civil society organizations, Governments and other relevant bodies.

59. The Independent Expert will conduct country visits, at the invitation of Governments, with the objective of learning about national realities and observing relevant laws, policies and programmes. Such visits will be an opportunity for the Independent Expert to identify best practices and areas for constructive dialogue with a view to enhancing the enjoyment of human rights by persons with albinism.

60. Furthermore, the Independent Expert will give particular importance to her mandate to conduct, facilitate and support the provision of advisory services, technical assistance, capacity-building and international cooperation in support of national efforts for the effective realization of the rights of persons with albinism and to prevent violence. She is therefore particularly committed to fostering capacity-building of national stakeholders, promoting exchanges on challenges and experiences and supporting efforts in translating

international norms into national legislation, policies, programmes and practices that are effective and adapted to national circumstances.

D. Increase awareness and understanding of the condition of persons with albinism

1. Awareness-raising

61. In line with her mandate, the Independent Expert will raise awareness on the rights of persons with albinism in order to combat stereotypes, prejudices and harmful traditional practices and beliefs that hinder their enjoyment of human rights and participation in society on an equal basis with others. To that end, she will promote positive change in social perceptions about persons with albinism through the dissemination of general knowledge about and understanding of albinism in society at large, including from a scientific perspective. Such awareness-raising will contribute to fighting myths and stereotypes about persons with albinism, particularly those that fuel stigma, discrimination and attacks.

62. Recognizing the limited capacity of most civil society groups representing persons with albinism, the Independent Expert wishes to work with them in order to increase their knowledge of national and international avenues for addressing the obstacles faced by persons with albinism in fully enjoying their human rights.

2. Research and data collection

63. Statistics and disaggregated data on albinism remain difficult to find, particularly in areas were the worst human rights violations against persons with albinism occur. In order to move towards policy changes, data collection, both qualitative and quantitative, and comparative analyses are fundamental in order to fully understand the current situation of persons with albinism.

64. In addition, the difficulty in accessing reliable data on cases of killings of and attacks against persons with albinism also hinders efforts to fight those horrendous human rights violations. Such data should include information on the number of cases registered, investigations, prosecutions and administrative and judicial decisions.

65. Similarly, understanding the root causes of attacks against persons with albinism is necessary in order to design strategies to address discrimination and attacks and to identify adequate prevention measures. The secrecy surrounding witchcraft practices and the underground nature of the market associated with the trafficking in body parts of persons with albinism make it difficult to find evidence. Understanding the phenomena and their implications would therefore be one of the priorities of the Independent Expert.

VI. Conclusions

66. **The Independent Expert views the creation of the mandate as a significant expression of the collective will to end attacks against persons with albinism and to find their root causes in order to establish measures to prevent the occurrence of attacks. As stated by the United Nations High Commissioner for Human Rights, "There is no room in this 21st century for erroneous and harmful beliefs, or for**

discrimination on any grounds. People with albinism are just as deserving of dignity as every other human being."[25]

67. **To that end and for the realization of all the goals established by the Human Rights Council in its resolution 26/8, by which it also established the mandate, she looks forward to engaging in constructive and fruitful cooperation with a diverse range of stakeholders in all regions, particularly and foremost in the areas affected by attacks on persons with albinism.**

68. **The Independent Expert reiterates her desire to engage constructively with affected States specifically to delve into the root causes of discrimination, stigmatization and attacks on persons with albinism so as to establish preventive measures. She also looks forward to various forms of in-depth engagement with Members States of the United Nations and emphasizes the importance of an inclusive and all-encompassing approach in the execution of her mandate. Finally, the Independent Expert notes the central and complementary role of civil society, particularly non-governmental organizations and academia, in providing her with necessary information for building sustainable platforms for the enjoyment of human rights by persons with albinism.**

---

[25] See "Statement by United Nations High Commissioner for Human Rights Zeid Ra'ad Al Hussein ahead of the first-ever International Albinism Awareness Day, 13 June 2015", available at www.ohchr.org/EN/NewsEvents/Pages/DisplayNews.aspx?NewsID=16072&LangID=E.